



Harm
Reduction



HIV/
AIDS



Rainbow
Space



Learn



Grow



Partner

HIV DISCLOSURE POLICY & PRINCIPLES

Approved: February 25, 2016

I. Statement of Commitment

CAYR COMMUNITY CONNECTIONS (CAYR) is committed to upholding the right to self-determined HIV disclosure throughout its programs and services and to their ongoing improvements to ensure they remain relevant to each unique client's unique needs.

II. Context/Background

CAYR serves both those dealing with disclosure and those who may be impacted by disclosure issues. Over the years CAYR has been called upon to provide counselling to many, responded to the media and dealt with multiple levels of judgment among clients and staff. Disclosure issues have been a stressor to the organization for staff, volunteers including board members, students, clients, as well as onsite and offsite partner agencies. Specific examples of stressors have included:

- Clients disclosing other clients' status outside of the agency;
- Clients bringing children and sexual partners to CAYR premises or gatherings without having disclosed their status to the accompanying individuals;
- Agency name being identified during referrals and on financial assistance cheques;
- External service providers and partner agencies not being able to apply a nuanced understanding of HIV disclosure in service delivery;
- Shared office and program space with community partners where community members may be present.

At the same time, we acknowledge the nuances and complexity of the context within which disclosure decisions may be made.

- Disclosure of HIV status is a life-long and complex process that changes and evolves over time.
- HIV disclosure situations can include disclosure to friends, family, service providers, employers, immediate community (e.g. geographic, cultural, religious), sexual partners and/or the public at large. CAYR staff will refer to and/or partner with other service systems where specific knowledge is required (e.g. housing, or family support). All disclosure situations can have some level of legal implication and as a result, it is appropriate to provide referral information to the HIV & AIDS Legal Clinic Ontario (HALCO).
- Specific circumstances such as changes in health, relationships, employment, broader determinants of health as well as increased or diminished personal capacity all contribute to disclosure decisions.

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- HIV disclosure happens in the context of life in broader society. In Canada, decisions are affected by the variable prevalence rates in different communities, by pervasive stigma based on HIV status, race, sex, gender and sexual orientation, as well as by the common discomfort that many experience in discussing disease, mortality and multiple forms of shame.
- Current Canadian criminal law means there is an additional legal context that can significantly affect HIV disclosure decisions, particularly in relation to sexual and drug sharing partners.
- Additionally, Ontario public health law can affect HIV disclosure by granting to health authorities the power to protect the public's health, and by placing a duty on some persons (doctors, nurses, teachers, or laboratory technicians) to report known and suspected cases of infection with transmissible diseases, including HIV and many sexually transmitted infections (STIs).
- At the same time, significant biomedical advancements are changing the disclosure discussion at personal, community, healthcare and public levels.
- CAYR acknowledges that in an environment where clients feel ready and/or safe to disclose, that process can be empowering and positively affect a person's life. Conversely, where clients are not ready or do not feel safe to disclose, pressure to do so is unhelpful and can even at times be harmful to the individual.
- While CAYR may, over time, experience changes of programs and staff, we are committed to stable, principled, relevant, and responsive programming.

III. Principles

CAYR upholds the following core principles as they apply to HIV disclosure decisions and actions:

- The **client's choice and right to self-determination** is the foundation of our response;
- Each client and their **circumstances are unique** and will be treated as such;
- People living with HIV/AIDS (PHAs) will experience a **non-judgemental** staff response to the expression of their needs and choices;
- Being careful not to push clients to make disclosures, **we will inform clients of our programming** related to HIV disclosure decision-making.
- **Referrals to and partnerships with other services** are critical to providing effective support;
- **Inclusivity of perspectives**, opinions and diversity of interests will inform all responses;
- **GIPA/MIPA*** will be reflected in HIV disclosure policy, practices and programming.
- **Ethical decision-making** standards and tools will be employed in HIV disclosure situations where the rights and interests of two or more people are in conflict, or where an HIV disclosure situation presents two or more competing values or principles – and where operational policy is incapable of providing sufficient guidance.

**GIPA/MIPA = Greater and Meaningful Involvement of People Living with HIV/AIDS*

CAYR commits to the following:

- Prominently posting and making available to all clients both this policy, and information about related programming options;

- Orienting all PHAs, other clients, staff, volunteers including Board members, students, and community partners who work onsite or visit agency premises to this policy and its associated programming options;
- Reviewing operational practices as part of regular evaluation cycles to ensure policy adherence;
- Ensuring a safe and supportive environment;
- Ensuring that we are competent at handling the complexities of HIV disclosure issues and at resolving the conflicts that may result from such disclosures.

IV. Program Standards

CAYR programming will include the following elements and topics to assist PHAs to control and navigate their HIV disclosure options, decisions and actions. The way in which CAYR implements these policies, including appropriate referrals at all steps and any current interventions being provided, is outlined in *Section V, Application of Program Standards & Principles*.

a. Reflection & Decision making:

- Self-acceptance – dealing with the impacts and personal feelings of an HIV diagnosis and experiences of living with HIV;
- Normalizing disclosure considerations, discussions and decisions;
- Educating PHAs and others about HIV with up-to-date information including biomedical advancements;
- Understanding legal implications, rights and responsibilities (as appropriately understood through information or formal legal advice such as HALCO);
- Acknowledging and exploring stigma and its impact on disclosure;
- Exploring potential safety issues in disclosure—for instance the potential for violence from spouses, family members, or for safety in housing or employment;
- Exploring cultural values;
- Identifying the individual risks, benefits, purpose and goals for possible disclosures;
- Supporting clients to resolve any ethical considerations in choosing to disclose or not to disclose;
- Making a disclosure list – exploring who could be disclosed to now, who might be disclosed to later and who might not be disclosed to;
- Determining whether to further explore specific disclosure situations;
- Exploring specifically how disclosure of a parent’s HIV status will affect children and adolescents;
- Exploring whether disclosure to a child or adolescent is done with proper preparation and support, and according to recognized standards;
- Ongoing reflection and review of disclosure journeys and processes.

b. Planning & Preparation

CAYR will offer planning and preparation support to clients that are ready, able, and/or willing to disclose. This includes but is not limited to:

- Maximizing benefits and mitigating risks;
- Testing the waters - hinting and probing for stigma, safety issues, and perceptions of HIV by those to whom the disclosure will be made;
- Disclosing to an ally – starting or testing disclosure with someone known to be HIV+ or known to be an ally;

- Where a decision to disclose is made, preparing a plan and strategies, i.e.:
 - Determining appropriate timing and setting – consider mental state of those involved, not being rushed, safety, and access to support;
 - Choosing a method or medium – the majority of disclosure experiences are face to face but consider if there are circumstances where another method or medium (phone? letter?) that might be beneficial;
 - Identifying the limits and boundaries of how much to disclose and share;
 - Tailoring disclosure message and content – type, duration and depth of relationship, recipients’ knowledge of HIV, reason for disclosing;
 - Consider and plan what and how much to share, particularly related to means of infection, stigma and/or trauma;
 - Preparing for possible responses;
 - Establishing personal support systems.

c. Support

In keeping with our commitment to upholding the right to self-determined HIV disclosure, CAYR will provide support to all clients including those who do not wish to disclose their HIV status. Support for clients that ready, able, and/or willing to disclose will include:

- Building confidence and capacity, including by practicing the disclosure and subsequent conversations. This may involve support in writing and verbal communication skills;
- Connecting PHAs to Peers and/or networks specifically related to disclosure decisions;
- Identifying potential support and/or referral information for those being disclosed to;
- Ensuring follow-up and support after the disclosure discussion.

d. Safety

- Reviewing possible responses and creating a safety plan;
- Identifying possible referrals and resources;
- Creating a safety plan for those who are not ready to disclose or have had their HIV status inadvertently disclosed by others.

V. Application of Program Standards & Principles

In making this policy work consistently across the organization, we are committed to applying standards and principles in the following areas:

a. Communication

- Prevention education programming will contribute to communicating the complexity of disclosure decisions and actions. This might be through the provision of legal information materials and will not include legal advice;
- All staff will be able to articulate the agency position and principles;
- CAYR communication will contribute to a recognizable agency culture that might prompt discussions and a sense of safety for clients in relation to HIV disclosure;
- The Executive Director will be notified immediately of potential controversial or politically contentious situations relating to HIV disclosure as they relate to employees, service users and volunteers—or of community events related to HIV disclosure that will

affect the organization and its clients. The Executive Director and Board Chair will be the principal spokespersons for the agency.

- Staff, volunteers including Board members, and students associated with the agency who wish to express personal views or opinions on this issue shall make it clear that their views are personal and in no way, the views of the agency;
- The Executive Director and Board Chair will be the principal spokespersons for the agency.

b. Service Integration & Points of Access

- Opportunities should be sought within CAYR programming to:
 - Name disclosure as an issue for which the agency provides support;
 - Communicate agency policy;
 - Respond to inquiries and requests with appropriate information, referrals and access to support.
- While all agency staff, volunteers including board members, and students can be potential points of access, the following particular opportunities exist:
 - During Intake;
 - Through general client check-in or re-assessment conversations;
 - While accessing practical assistance programming;
 - As part of support services;
 - During Poz Prevention sessions; and
 - Online outreach.

c. Training Goals:

- All training participants will have found the training to be a safe place in which to discuss and learn the agency's position, and its rationale;
- Staff, volunteers including Board members, and students will be able to articulate the agency position and be skilled in using the policy to increase knowledge of the complexities of HIV disclosure within, and external to the agency;
- Newly oriented staff, volunteers including Board members, and students will clearly understand the agency's expectations regarding their duties of confidentiality and privacy of client information, and the limits, if any, of these duties. Staff belonging to regulated professions will also be clear as to the expectations of them;
- Additional training, specific to legal issues related to HIV disclosure will be regularly offered by HALCO.

d. Monitoring and Evaluation

The organization will monitor and evaluate its capacity and expertise in supporting clients in HIV disclosure decisions.

e. Legal Questions

- CAYR staff will proactively refer all legal questions and discussions to appropriate partners such as the HIV & AIDS Legal Clinic Ontario (HALCO);
- Employees and volunteers will not give legal advice to clients, nor will they give personal opinions regarding any related circumstance surrounding HIV disclosure or the overly broad criminalization of HIV non-disclosure.

f. Trauma Informed Response

CAYR will support staff to be informed of their roles - including their role in making appropriate referrals - when responding to disclosures of trauma that may emerge in the course of HIV disclosure decisions and actions.

g. Staff, Volunteer & Student Disclosure, and its Effect on Clients

CAYR is committed to managing the effect of staff, volunteer and student HIV disclosures on our programming. In so doing, we have a primary organizational duty to clients, while upholding the principles of GIPA/MIPA in supporting our staff, volunteers (including board members) and students. CAYR will:

- Ensure that staff, volunteers including Board members, and students understand how the disclosure of their HIV status could have unintended consequences for clients. Staff, volunteer and student disclosure of their HIV status can contribute to creating a safe space, can increase peer connection related to the lived experience and can positively influence supporting the client. Staff disclosure can also, particularly where staff don't follow appropriate boundaries and share specific details of their HIV disclosure choices, either unintentionally burden the client, or unduly encourage them;
- Support staff, volunteers and students who choose not to share their HIV status with clients (including supporting Board members or volunteers to decide whether or not they wish to publicly represent the voice of PHAs/ the agency).

h. Disclosure Dilemmas

CAYR will implement a concrete process to deal with ethical dilemmas that arise for staff around HIV disclosure issues—whether they are related to their own HIV disclosure, or client HIV disclosure. These are dilemmas where the rights and interests of two or more people are in conflict (perhaps two or more clients or two or more people known to the organization), or where an HIV disclosure situation presents two or more competing values or principles.

i. Disclosures to Children

- There are special disclosure considerations related to children. Best practices exist and CAYR will remain informed of these and refer appropriately;
- Some of the many unique circumstances that arise around children and family HIV disclosure include:
 - There are increased points of vulnerability and loss of control during pregnancy process, which expand with increased access to the health care system;
 - Disclosure questions and judgements related to infant feeding ;
 - Understanding child development and age-appropriate processes/messages/resources (*How Do I Tell My Kids: The Teresa Group & CATIE, 2015*);
 - Because of inconsistent responses within school systems, there can be significant fear that any family disclosure may negatively affect the school environment and result in possible discrimination;
 - There is an increased risk of unintentional disclosure, particularly where disclosure has occurred with some but not all family members;
 - Tensions between the HIV-positive parent's right to confidentiality and a child or teenager's need for support;

- Additional complexities and lack of control for children who are wards of the state;
- Inconsistent knowledge, interpretation, training, assumption and responses in other health and social service systems such as Children’s Aid Society.

j. Record Keeping

- Record-keeping requires balancing the need to keep records with the desire to protect client confidentiality given the risks of data breaches and involuntary disclosures in the cases of search warrants and subpoenas.
- Staff will discuss with Executive Director anytime there is uncertainty of the level of detail or content to include in client records related to HIV disclosure.
- CAYR will develop procedures to minimize the amount of information that must be disclosed when issued with search warrants and subpoenas.

k. Housing

- HIV disclosure can be significantly complicated by situations related to housing. Some of the unique considerations that CAYR will be attentive to include:
 - A PHA’s residence: the disclosure of their address can precipitate unwanted disclosure or assumed disclosure from community or other tenants;
 - Accessing supportive housing services: this may prompt disclosure or assumed disclosure;
 - That HIV status disclosure is required for Priority Status Access to municipal housing;
 - That some shelter system policies and practices (such as handing in medications to shelter staff) structurally force disclosure;
 - That those physical altercations where one or more tenants in a supportive housing situation are a known client (or staff/volunteer/student) may result in police investigations and questions for CAYR.
- Long-term care facilities and appropriate training and support related to HIV disclosure of residents, particularly where dementia is a complicating factor;
- Staff will develop strategies to best support clients to maintain control of their disclosure decisions as we assist them in their efforts to be better housed.

VI. Related Policy & Procedure Review

The following related Policies & Procedures will be periodically reviewed to ensure that they are consistent with this policy:

1. Service User Rights & Responsibilities;
2. Client record keeping;
3. Confidentiality;
4. Human Resource policies related to disclosure decisions of HIV+ staff in the work environment, in public, or on social media;
5. Volunteer policies related to HIV+ volunteers;
6. GIPA/MIPA policies;
7. Policies or procedures related to designated PHA roles within the agency such as designated staff positions (i.e. Speakers Bureau Coordinator) or designated PHA volunteer positions (i.e. designated PHA seat on the Board or Speakers Bureau member);
8. Agency position statement on Criminalization of HIV Non-disclosure.